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## **'Me and the 5 P's': Negotiating Rights-Based Critical Disabilities Studies and Social Inclusion**

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### **Abstract**

This paper presents an integration of insights from critical disabilities studies, child rights and social exclusion in theory and practice and is conceptualized from two keynote presentations given by Dr. John Davis and Mr. Luke Melchior at *Investment and Citizenship Towards a Transdisciplinary Dialogue in Child Rights*, at Brock University Canada. In addition, the lived experience of disability is at the centre of this discussion rather than being the object of inquiry, providing a nuanced experiential perspective. The aim of this collaboration is to emphasise that young peoples' rights from the perspective of critical disabilities studies may be informed by an analysis of power relations and the five principles of protection, prevention, provision, participation, and perception (5 P's).

### **Keywords**

children's rights; critical disabilities studies; social solidarity discourse; social inclusion

### **Introduction**

Building upon keynote presentations during *Investment and Citizenship: Towards a Transdisciplinary Dialogue in Child and Youth Rights*, this paper discusses lived experiences of disability from a framework of child rights, social inclusion and critical theory. Lead author Dr. Shannon Moore is an Assistant Professor of Child and Youth Studies at Brock University with a research focus on critical social pedagogy and child rights. She contributes insights from her practice-base in counseling and her work with young people with disabilities. Mr. Luke Melchior is an advocate on behalf of persons with disabilities and is a person living with a severe physical disability as a result of Duchenne muscular dystrophy. Mr. Melchior's standpoint is informed by his childhood experiences living in institutional care and from his current perspective as a social activist and education developer

for Muscular Dystrophy Canada. Dr. Moore met Mr. Melchior two decades previously in an earlier role as child and youth care professional at a Canadian children's hospital. Dr. John Davis is a Senior Lecturer at the University of Edinburgh with extensive experience in ethnographic and participatory projects related to social inclusion, disability studies and child rights.

Accordingly, the lived experience of disability is at the centre of this discussion rather than being the object of inquiry, and has facilitated the uncovering of a nuanced critical perspective (Biklen, 2000) on both experience and discourse. The aim of this collaboration is to re-emphasize that young people's rights from the perspective of critical disability studies may be contextualized by power relations and the five principles of protection, prevention, provision, participation, and perception (or 5 P's). This standpoint extends previous conceptualisations of child rights principles (Mitchell, 2005; Van Bueren, 1998) to include the integral impact of human perception within the social-political world of young people living with disabilities.

To achieve this aim, the paper is organised in several sections. First, a foundation is offered by considering critical disabilities studies in the context of social exclusion and child rights. Then, the focus turns to an experiential discussion of protection, prevention, provision, participation, and perception framed within critical discourse. Finally, this paper concludes with a critical reflection on the challenge of negotiating rights-based critical disabilities studies while tentatively affirming forward directions that could contribute to fuller expressions of social justice.

### **Towards Critical Disabilities Studies: Negotiating Social Exclusion**

Through the lens of critical theory, social exclusion is essentially a product of unequal power relations embedded within the institutions making up contemporary society in both the developed and the developing worlds – also known as the minority and majority worlds. The obstacles experienced and managed by individuals experiencing disability are factors implicitly taken for granted as rights for the majority of citizens: ergo an ideology of disability as dependent and deficient is created (Oliver, 1998). Indeed, social exclusion and social inequality remain dominant experiences for many young people living with disabilities the world over. Lansdown (2005) confirms this point in the following reference to the recent drafting of a UN Convention for people with disabilities:

Despite the unique provision in the CRC which explicitly includes disability as a ground for protection from discrimination, children with disabilities continue to face extreme forms of discrimination in most countries around the world. Analysis of government reports to the Committee on the Rights of the Child reveals that virtually the only issues ever addressed by governments in respect of children with disabilities relate to education and social welfare.

Other rights — to participate, to play, to information, to freedom from violence, to an adequate standard of living, and indeed, the right to life are rarely, if ever, addressed. It is therefore imperative that this new treaty pays attention to children as well as adults with disabilities in imposing obligations on governments to ensure that all people are afforded equal respect for their rights (p. 1).

Clearly, the recent drafting of a UN Convention for People with Disabilities may address the discrimination described above in a manner that extends previous effort made by advocates and researchers applying the Convention on the Rights of the Child. This paper also includes critical social pedagogy as a discourse that may deepen understanding of the lived experience of disability and inform social justice efforts within research, policy and practice arenas.

Critical social pedagogues have established a post-structuralist turn towards understanding the body as site for political and cultural activity (Giroux, 2003; McLaren, 1988; Moore, 2006), yet there is persistent dearth of research exploring the subjective experience of disability from within this critical discussion (Erevelles, 2000). Gabel (2002) notes further:

Critical pedagogy cannot be considered fully inclusive until its discourse begins to account for people of diverse abilities ....[persons] who differently express “voice,” whose pace of life or movement through time and space are highly diverse, and whose bodies look and function in diverse ways. Perhaps most dramatically, considering ability diversity requires us to quiet dogmatic discourse and listen for the preferences and interests expressed by people who have a wide range of references and interests (p. 196).

This curious segregation within established discourses underscores the challenges inherent in synthesizing greater understanding through disability studies, subjectivity and critical theory (Biklen, 2000) aimed towards promoting the rights of young people in a manner that leads to social inclusion for all. Although the term social exclusion has been criticised as ‘too vague’ (UN Commission on Human Rights, 2000) because it is indicative of a range of contexts such as the effects of poverty or social interactions (Hill *et al.*, 2004), the lived experience of social exclusion is articulated by Melchior below while the notion remains complex:

I was born with Duchenne muscular dystrophy, a severe muscle-wasting disease that put me in a wheelchair at the age of ten and on a machine to help me breathe at the age of eighteen...Needless to say, my disability has not gone unnoticed by anyone around me. Some people stare at me, others pity me, and still others offer me their opinions and advice - some of which is positive and constructive, while the rest is down-right pessimistic. Regardless of their intentions, each of their messages is heard loud and clear ... What I would have been, had I internalized all of the negative messages put forward by professionals and the rest of society: *uneducated, unworthy, uninvolved, unemployed, unaware, unattractive, under-housed, under-funded - six feet under.*

In fact, multiple discourses such as the social model point to the need for social justice through removal of environmental barriers to local spaces, leisure, education

and work for persons living with disabilities. The development of strategies that challenge poverty through income redistribution, and growth of approaches that promote resilience, involvement and participation point to this paradigmatic shift in ideologies of disability. This is reinforced if we transcend false dichotomies of ability-disability while taking up a critical thinking in order to reconstruct ideas of social inclusion, children's rights and social justice as interactions and reactions to the production of knowledge, space, power, politics and change (see McIntyre, 2005).

*Social Exclusion: Individual Responsibility or Social Barrier*

Writers in political studies in the UK and US have tied the concept of social exclusion to a Moral Underclass Discourse (Levitas, 1998). This discourse relates social exclusion to a decline in moral standards, blaming children's poor educational achievements on their parents (specifically teenage and single mothers), the media and disintegration of social ties (Murray, 1990). By concentrating on the limitations of individuals this writing tends to separate out and stigmatise specific people. Politicians and academics in the late 1980s and early 1990's in both the UK and US latched on to the analysis of blaming families and specifically women for the failings of society. For example, Coleman (1988) defined working mothers and lone parents as causing exclusion (see also Morrow, 1996, 1999). These ideas have subsequently been refuted by studies that show the benefits to children of working mothers, high quality child care provision and well qualified education/care staff (Skinner, 2005).

Indeed moralist discourses tend to be characterised by a lack of engagement with the views of those they perceive to be excluded or cause exclusion. However, Saranceno (2001) makes a strong point when suggesting that moralist discourses also overlook the diverse and implicit nature of cultural values. By blaming parents and communities for the failure of children and young people to thrive and succeed, moralist discourses ignore the possibility that many (those from working class, disabled and ethnically diverse backgrounds, for example) actively reject educational institutions, not because their value system is immoral, but because they experience discrimination and a lack of recognition within these social settings (Davis *et al.*, 2003).

Such moral underclass discourses have been recently contrasted with social integration discourses that define the excluded as those who are prevented by social circumstances from accessing education, employment or local services. We can now simplistically characterise the differences between these two discourses in terms of the clash between objectifying/blaming people who experience poverty, and considering that poverty is caused by factors beyond the individual like lack of access to employment and education. Others such as Cockburn

(2002) argue that this distinction often results in ineffective social policies that do little to challenge the root causes of inequality. This distinction is similar to that made between social policies aiming to provide opportunities for ‘integration’ into the same social spaces, and those that actually aim to enable ‘inclusion’ defined as ‘equality of experience’ within the same social spaces (Davis and Watson, 2001; Davis *et al.*, 2003).

Social exclusion perspectives that examine ‘equality of experience’ attempt to balance both materialist and socio-cultural ideas of inclusion whereas materialist approaches tend to classify or count disability, and social-cultural approaches focus on the search for meaning (see Oliver, 1998). Levitas (1998) suggests that social exclusion perspectives relate to French concepts of social solidarity and perceive exclusion to stem from people having limited social ties. The authors of this paper refer to this perspective as the ‘Social Solidarity Discourse’, and thus, make a distinction between individual and social barriers to full inclusion. This distinction is familiar to scholars within disability studies who have argued that medically-based (modernist) discourses have traditionally concentrated on disabled people’s individual (in)ability, and this has led to medical professionals monopolising resources and creating cultures of dependency (Barnes, 1991). Hence, “ideologies perpetuate barriers and exclusions” (Oliver, 1998, p. 1448), and result in “messages” impacting those living with disabilities illustrated and discussed by Melchior above.

Furthermore, disabled people have begun to redefine the word *disability* to highlight the inequalities they experience within society:

In an effort to counter discrimination and powerlessness, the disability community has espoused sociopolitical and cultural factors as defining characteristics of disability identity. This view of disability has replaced the historical medical model of disability as deficit, and has important implication for social action, political agendas, legislation and overall quality of life for individuals with disabilities (French Gilson and Depoy, 2000, p. 207).

Similarly, the Union of the Physically Impaired Against Segregation (1976) stated that disability is caused by contemporary social organisation that excludes them from participation in the mainstream of social activities (this became known as the ‘social model of disability’). This shift has enabled disability to be re-characterised as a form of social oppression that prevents disabled people’s inclusion in society (Barnes, 1991; Barnes *et al.*, 1999; Oliver, 1990; Finkelstein, 1993; Campbell and Oliver, 1996; see also Linton, 1998 for an American analysis of ‘social model of disability’). Emergent writing by disabled people, such as Melchior in this paper, are facilitating this cultural, political and theoretical transformation from viewing personal limitation faced by individuals as the social restrictions and politics of power in dominant society (see also Oliver, 1998).

## Me and the Five P's: Reflections on Self Advocacy and Power

The plethora of historical knowledge about disability has been framed by health science research on impairment and positivistic ideologies (Oliver, 1998) so that today many young people still remain objectified within society rather recognized as competent social actors and agents of social change (James and Prout, 1997). The impact of ideological standpoints that buttress the barriers between adults in authority and young people with disabilities are then reinforced in the lived institutional experiences of children (Mitchell, 2003; Scraton, 1997). In this way perception shapes adult-child power relations and experiences of participation, the provision of care and distribution of resources, constructions of harm, protection and prevention. To secure the rights of children with disabilities we need "sounder knowledge of children's lived experiences" and their unique social contexts (Childwatch International, 2006, p. 1).

### *Participation*

Similar to social exclusion, participation has many definitions (Kirby *et al.*, 2003). At its essence, participation also enables children and young people to contribute to processes of change and/or cultural transformation. As a basic principle of the Convention on the Rights of the Child, Article 12 articulates rights-based social action simply: all young people have a right to fully participate in matters that impact them and to experience their views being heard. Clearly, participation contrasts 'consultation', the latter centres solely on listening to children and young people (for further discussion see Lansdown, 2001; Borland *et al.*, 2001; Davis *et al.*, 2003; Mitchell, 2005; Tisdall and Davis 2004; Whiting, 2004).

Furthermore, authentic participation in the context of the CRC and critical disabilities study demands a movement away from the medicalisation of childhood (Mitchell, 2003) and modernist ideologies of disability as deficient (Oliver, 1998). Melchior confirms this in the following:

When the Eighties were drawing to a close, an important paradigm shift began to take place at the institution, a change that would ultimately save my life. Whereas I had previously been treated as a passive object of care, I was now being seen more as an active participant in my life.

As with most advances in thinking, this one happened because new faces were installed in key places. Out went the Draconian staff who thought that solitary confinement was a good teaching tool, and in came the 'humans' (as I called them) who believed in our value as human beings - not just as names on the bowel movement chart that hung on the wall (although they did keep using that damn chart).

Two of these humans deserve particular mention. A physiotherapist named Kelly Comer saved my life and a child and youth care named Judi Bougie made my life. Kelly had been so upset that my friend Kasai died that she researched all the latest treatments for people with my disability and subsequently lobbied the institution to offer us assisted ventilation. You may



wonder why I have included her story in a discussion about participation. The answer is quite simple - she believed that people like me deserved a chance to participate fully in society and recognized that the best way she could help was to find a way to keep us alive.

Judi believed the same thing but knew that the best way she could support us was to offer us support - support to reach whatever goal we had in life once we knew we actually had a fighting chance to live. In my case, Judi helped me write a successful grant proposal and co-chair an international conference all by the age of 21. Those accomplishments gave me the confidence and opportunity to do all the things that have led me here, to be one of your keynote speakers. So as you can clearly see, true involvement can lead to true citizenship.

Likewise, critical social pedagogues have identified participation as closely linked to power relationships and increased opportunities for self-advocacy (Mitchell, 2005; Moore, 2006). Simply put, there are direct relationships among young people's meaningful opportunities to participate and be heard, and their impact on cultural transformation and social action.

### *Provision*

Of course another form of participation involves self advocacy, and this enables children and young people to identify their own goals and develop their own solutions to their every day life issues (Whiting, 2004). Linked to participation, a poignant example of self advocacy is illustrated by Melchior who as a minor lived at children's hospital and a hospice for young people with muscular dystrophy. It was also there as a young person he began his role of advocate for self and others with disabilities. He relates this as a story of 'provision':

In the Eighties, the institution I visited (and later lived at) provided food, lodging, personal care, medication, physiotherapy, and a number of other services, but sadly it failed to support the use of life-saving measures when it involved residents with my type of disability. One by one, all of the people with Duchenne muscular dystrophy that I had befriended over the decade were allowed to die when their lungs were no longer able to draw in enough air to sustain life. Mark, Jerry, David, Shawn, Cam, Michael, Richard and Kasai each slipped into a comatose state as the level of carbon dioxide in their bloodstream reached a lethal level, causing them to die in a matter of hours.

Out of all those friends, the one whose death caused me the greatest pain and anger was that of Kasai Parsons. The reason for this was that only a few months prior to his death, the staff of the institution had stumbled across the very life-saving measures that could have prevented his demise. While on a trip to Disneyland, Kasai had suddenly fallen into respiratory distress and was rushed to a local hospital. As soon as he arrived in the emergency department, he was assessed and subsequently hooked up to a ventilator to assist his breathing. The machine turned out to be such an effective treatment for his symptoms that by the end of our trip, he had fully recovered and was able to rejoin us for the journey home.

Once we had returned to the institution, however, his condition quickly started to deteriorate again. This is where the story becomes heart-wrenching. Despite what was learned in California, no one thought to put him on a ventilator this time. It was as if his successful treatment had been erased from everyone's minds. Instead, the medical-minded nurses at the institution went into automatic pilot mode and did what they had done every other time, nothing except comfort the dying patient. No ambulance was ever called and no life-saving were ever attempted. And so it was that Kasai slipped into a cerebral haze and died.

The most maddening aspect of each death was the blatant lack of attention paid to trying to prevent such tragedies from happening again. An incident report was always written for mundane things like a forgotten dose of stool softener or an unsupervised trip off of hospital property, but not for someone dying! If they didn't care about us dying, why did they bother with all of those other fucking reports?

My theory is that it all has to do with the risk of liability. If someone was not given their dose of medication and it was written up, but then the client died as a direct result of the error, the institution could say that they did as much as they could in the situation and would be off the hook from a liability standpoint. Contrast this with someone dying of their incurable terminal illness because no aggressive interventions were attempted. The institution could just say that the patient died of natural causes.

Based on the tragedies I have witnessed, I believe that a child's right to the provision of the essentials of life is subjective. It seems to depend on a combination of factors including the child's prognosis, perceived quality of life, and their access to information. For example, the conventional wisdom regarding Duchenne muscular dystrophy has been that it is terminal at an early age, that it results in a very low quality of life, and that there are no known treatments for it. Consequently, the traditional course of action in this situation has been to make the patient as comfortable as possible until the inevitable occurs. It sounds noble when considering such outdated assumptions, but if you were to do even a cursory literature review, you would quickly change your thinking.

In light of Melchior's testament regarding provision rights, it seems an understatement to reflect that children and young people are simply frustrated they do not have more control over their immediate environment (Christensen and James, 2000; Morrow, 2000). If the views of Melchior and his cohort were heard in a timely manner it is easy to speculate that a different understanding of the principle of best interests articulated within CRC Article 3 might have been deployed. In fact, if young people with disabilities have opportunities to develop their own treatment plans, goals and solutions, their diverse ways of knowing could expand cultural transformation toward authentic rights-based social justice benefiting whole communities.

Indeed, recent research has found that children are deeply aware of discrimination against other groups of children, and feel that they were given 'lesser' status than adults and disregarded during the development of public policy. In response to this experience children wanted to play a greater part in contributing to policies and legislation which could impact on their lives (Lansdown, 2000). This perspective defines one type of social exclusion as children's choices and wishes not being recognised by parents, teachers, policy makers or researchers (see also Alderson 1995; Morrow and Richards 1996; Davis *et al.*, 2003).

### *Protection*

Contextualized by notions of children's rights and critical disabilities studies, the principle of *Protection* is found to be closely bound to the principles of participation and provision described above. This link is established further by Melchior's lived experiences:

Health care policies and government legislation relating to the care of children became omnipresent from the moment I first started receiving respite care from the local institution for

children with disabilities. Any time I did anything that was unexpected there like (god forbid) leave the hospital grounds without supervision, what I like to call the “ass cover and sanitize” policy kicked in and an incident report was written. Interestingly enough, the acronym for the report was SOAP - which stood for Subjective, Objective, Assessment and Plan. I guess the old “wash your mouth out with soap” approach to punishment has left an indelible mark on previous generations.

Anyway, protecting children's rights appeared to be synonymous with removing all opportunities for risk. Risk was seen to have a direct and inverse relationship with protection. Increasing protection meant reducing risk. What they failed to realize was that trying to wipe out risk completely was and always will be a losing proposition. There will always be risk as long as there is free will. You can legislate behaviour and maybe even reduce it, but you can't prevent it completely.

Evidently, protection of young people with disabilities creates a tension in adultist institutions charged with the provision of care; and, in response, the right to participation, to play and to other freedoms are violated (Lansdown, 2005). This scenario appears similar to experiences of young people in conflict with the law, or those incarcerated in secure custody that find their basic human rights violated as protective measures, and best interests dictated by adultist contexts through experts (Moore and Mitchell, 2006). Thus, CRC participatory principles found within Article 12 and non-discrimination within Article 2 are devalued.

### *Prevention*

Many authors note that the core principles of the CRC are interconnected (Mitchell, 2005) and are shown in Melchior's discussion of participation, provision and protection. Still, prevention from future harm uniquely resonates for child and young people with diverse abilities. In the available literature, it is also well established that young people with a range of disabilities are more likely to be sexually, physically or relationally abused across cultures and national contexts (see for example Kvam, 2000; Sullivan and Knutson, 2000). At the same time, legislation and policy aimed at preventing these varieties of abuse and harm are a standard of care in countries such as Canada, the United States and the United Kingdom. Hence, one is compelled to consider where more effective prevention mechanisms might be established if young people had opportunities to actively participate in the creation and implementation of policy texts as they directly impact power relations within institutions (Moore and Mitchell, 2007a,b; Scraton, 1997). Melchior confirms this point in the following:

In theory, the plethora of policies that were in place at the institution should have more or less protected me and my fellow residents from harm. Unfortunately for us, however, this was not the case. When I first stayed there in the mid-Eighties, or as I like to refer to them “the Dark Ages”, abuses occurred often. Whenever we had been deemed to have misbehaved badly, our punishment was to have our wheelchairs disengaged so that we couldn't move and then we would be left in our rooms with the door shut. In other circles, this would be called “solitary confinement”. I guess we were convicted criminals and didn't know it at the time.

This was small potatoes compared to another uncomfortable situation I found myself in. On one occasion, a staff member invited two of us over to his house for a sleepover with promises of good food, good games, and a late bed time. To a pair of fifteen-year-olds, this was a deal too good to refuse, so off we went. After an evening that lived up to its billing, it was time for bed. I thought to myself, okay so I guess he has a few extra beds here for us to use. As he started to move furniture out of the way in the living room to make way for a makeshift bed consisting of various sheets and pillows, I sadly realized that I was mistaken. The two of us would be sleeping on the floor.

So then the careworker proceeded to get us ready for bed. Feeling uncomfortable, I decided to keep my t-shirt on. My friend, on the other hand, took all of his clothes off. The only saving grace for me in that awkward situation was that my friend had been placed a full body's width away from me. Where I had thought the careworker had done this as a courtesy to me, his real intentions soon became all too clear. After getting us set up, he disappeared, presumably to go to his own bedroom for the night. A few minutes later, he returned wearing nothing more than a white tank-top and a pair of boxer shorts. He then proceeded to lay down between us. At that moment I turned white with fear and suddenly felt nauseous with regret for having made such a grave error in judgment.

Luckily for me, though, he didn't lay a hand on me that night. When we left the next day, I vividly remember memorizing our location in case he ever tried to do anything to us in the future. Since I was only an infrequent visitor to the institution, I had no idea how often my friend or other residents had gone over there for sleepovers nor what happened on those occasions. I never told anyone what happened that ill-fated evening because I felt like I was that careworker's friend and I didn't want to get him in trouble. However, as an adult looking back on the situation, I now realize that I should have said something if only to prevent it from happening to others.

Avoiding abuse is impossible when the prevention mechanisms being used are reactive in nature. At the institution, a harmful incident had to take place at least once before a plan would get made to help prevent it from reoccurring. Where did all the SOAP go? With accidents, this could be seen as a reasonable policy, but when it came to abuse, I believe it fell far short. One incident of abuse is one too many in my opinion. Where a broken leg can mend in a matter of weeks, the emotional damage caused by abuse can take a lifetime to heal.

In brief, avoiding abuse may be impossible when prevention mechanisms are simply reactive. As Melchior makes abundantly clear, processes that address prevention could be made more effective if young people living various experiences of disability had opportunities to participate authentically in crafting practice standards and policy texts that impact daily living so profoundly. Similarly, both the UN Committee on the Rights of the Child and the Council of Europe have published documents that set out how children can be involved in service planning (see also Stevens, 2008, this issue). The European Youth Centres and Foundations also act as resource/educational institutions that have encouraged the development of non-governmental youth organisations to enable young people to contribute to decision making within the European Union.

Sinclair and Franklin (2000) suggest that children and young people should be involved in decision making in order to: uphold their rights as citizens and service users; to enable politicians to fulfill legal responsibilities related to international and national legislation; to improve and influence services through better informed decision making; to enhance democratic processes; and finally, to promote protection from abuse. Similarly, Kjörholt, (2002) argues that the benefits of participatory projects help children and young people to develop their own identity, a sense of

social justice, and the ability to self-empower. As is the case in many European nations, where it has been argued that children and young people want to be involved in issues that affect them because it offers the opportunity to develop new skills and tackle abuses of their rights. In Canada and the US, this type of rights-based policy and practice is not yet well established. As is the case in much of the literature; it is suggested here that children and young people feel they have a lot to say and want to contribute to making the world a better place (Lansdown, 2001).

### *Perception*

As discussed in the introduction, a central contribution of this paper brings forward the idea of perception as a proposed fifth principle of child rights. Here, perception is considered under the rubric of self and identity and linked to participation, provision, prevention, protection. Melchior explains this interconnection:

Beyond creating opportunities for participation, providing rights, preventing abuse, and protecting child's rights, adults also have a responsibility to teach children to perceive their own inner worth. After all, if children felt as entitled to the full array of human rights as everyone else, they would accept no less. In this way, children would no longer feel obligated to define their expectations according to the limited imagination of adults, especially those who call themselves professionals.

As an adult who feels the weight of this perceptual responsibility, I recently held the position of national ambassador for Muscular Dystrophy Canada. In my capacity as ambassador, I was given a platform to share a life-changing story with people across the country. I feel it would be fitting to close my presentation by sharing that story with you now...

During an outdoor gym class when I was only seven years old, the teacher told us to complete three laps around a long row of bike racks. As expected, my inability to run quickly landed me in last place. To make matters worse, some of the kids were already beginning to lap me. Feeling frustrated, I dropped my head and began to stare at my feet as if to compel them to move faster.

While I was peering down at the ground, something shiny suddenly caught the corner of my eye. Being the curious kid that I was, I had to move in for a closer look. The fact that I was in the midst of a race didn't seem to faze me at the time. So without a second thought, I found myself down in the manicured grass reaching for the tiny treasure. It wasn't until the object was safely in my hand that I realized what I had found. It was a quarter!

By the time I made this discovery, the fastest kids had already finished the race. Instead of being disappointed with my own progress in the race, it so happens that I was the happiest kid in the school yard. Why was I in such good spirits you might ask? Well, it's quite simple really. Although everyone else would finish the race ahead of me, I was twenty-five cents richer!

As Melchior shows, perception of self and identity are shaped within our social worlds and greatly impacted by the ideological frameworks of parents, guardians and professionals who in turn impact the lives of young people. For instance, Melchior describes "what I really am" today is the result of his belief in 'self' and the opportunities for inclusion of all individuals facilitated in his Vancouver Island community:

A high-school AND college graduate; exceedingly handsome; living independently; a business owner; a retired athlete; a world traveller; a community activist; a former national ambassador for Muscular Dystrophy Canada; alive and kicking; and recently married.

Melchior's poignant and provocative illustration of a 5th P - the principle of perception - affirms that for persons living with diverse abilities, the body is linked to identity politics and human rights in a manner entwined with underlying psychological, social and political constructs (Putman, 2005). In this way, we can extend social models of disability and emerging notions of child and youth rights through the lens of critical theory, and provide new understanding that young people's identity, self-perception and lived experience of citizenship are shaped and re-shaped through social forces and public policy.

To close, the central thesis of this paper considered lived experiences of individuals living with disabilities in the context of child and youth human rights, social exclusion and critical theory discourses. This framework for rights-based critical disabilities studies ushers forth notions of solidarity, social bonds, conflict, hierarchy and implicit power relations. Framed by these 5 P's - the principles of protection, prevention, provision, participation, and perception - it becomes clear that inequality based on a lack of access to social rights for young persons with diverse abilities persists despite the almost universal ratification of the CRC. As the challenge of social inclusion and human rights for young people with diverse abilities continues to be negotiated, it is possible to identify some movement. Understanding the lived experiences of people with diverse abilities as the most valuable resource in social change, as well as the drafting of the UN Convention for People with Disabilities and the use of the CRC as a framework to guide implementation of a rights-based approach, together may facilitate socio-cultural transformation.

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